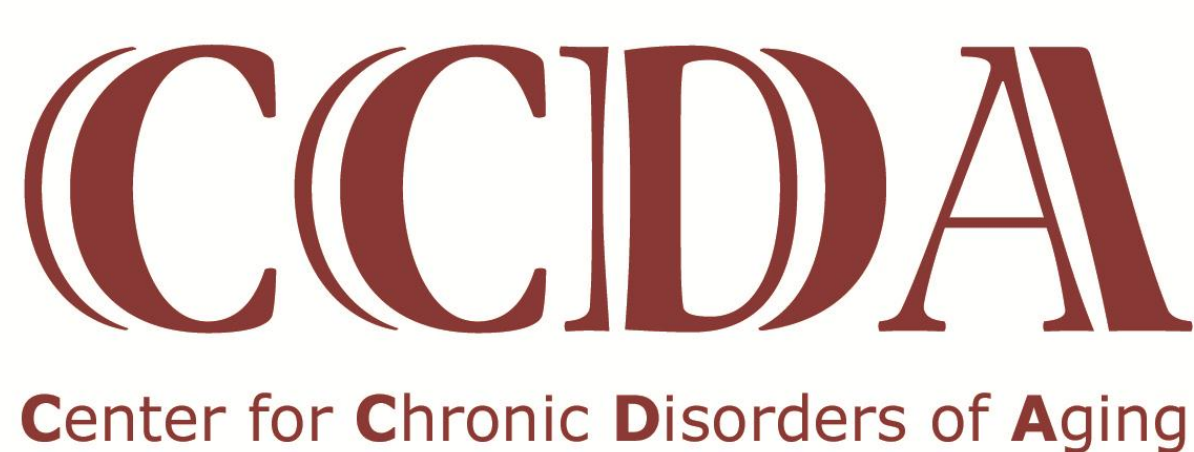


QoL in Child LQTS Patients Compared to Cardiac Patients



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Introduction

- Long QT Syndrome (LQTS) is a life threatening genetically-inherited cardiac arrhythmia disorder affecting approximately 1:2500 persons¹, often diagnosed in childhood.
- Management of LQTS changes patients' lifestyles which can affect quality of life (QoL). Patients have **restrictions** in **physical activity**, **diet**, treatment of noncardiac conditions; take **daily doses** of **medicine** and/or **have implantable cardiac devices** (pacemaker/defibrillator).
- General pediatric cardiac patients show significantly worse QoL in comparison to healthy controls^{2,3}.
- Nearly **1 in 5** with other cardiac disorders **reported impaired psychosocial functioning**³.
- The effects of implanted cardiac rhythm devices in cardiac patients demonstrated a significant effect on QoL in pediatric patient scores⁴.
- LQTS patients** are typically **not assessed** for **psychological** symptoms.
- Little research on QoL in pediatric LQTS patients has been conducted to determine if psychosocial interventions are warranted.

Methods

- IRB approval was obtained at both PCOM and CHOP, as part of a larger study.
- Participants: 24 children, \bar{X} =13.4 years; 58.3% female, 95.8% Caucasian.
- The Cardiac Module of the PedsQoL was given along with other questionnaires measuring psychosocial functioning.
- Measures were completed an average of 5.59 years after receiving the diagnosis of LQTS.
- 39.1% of participants had been symptomatic since receiving the diagnosis.
- 100% of the patients are currently taking cardiac medication.
- Z scores were used to compare the dimensional scores for children diagnosed with LQTS to the norms for the Cardiac Module of the PedsQoL⁴

Table 1. Characteristics of LQTS Patients and Normed Group

	LQTS Patients	Normed Group
Age (in years)	\bar{X} = 13.4	\bar{X} = 9.0
% Female	58.3	40
% Caucasian	87.4	95.8
Taking Cardiac Medication	100%	31.50%
Been symptomatic	39.10%	n/a
Time since diagnosis	\bar{X} = 5.59 years	unknown

Results

- No significant differences were found on the Heart Problems, Physical Appearance, Treatment Anxiety, and Cognitive Problems Dimensional Scores.
- Communication scores were different and was more of a concern for LQTS patients

Table 2. Differences comparing normed scores and LQTS scores on PedsQL Dimensional Scales

Dimensional Scale	Normed Score ¹	LQTS Patient Score	Z Test	p
Heart Problem	76.02	76.09	0.0201	0.492
Physical Appearance	79.34	80.43	0.2105	0.417
Treatment Anxiety	76.09	82.26	-1.36	0.088
Cognitive Problems	75	75.66	-0.157	0.44
Communication	70.65	78.84	-1.74*	0.041

¹Normed scores from Varni (2005) * $p \leq .05$

Conclusions

- Similarities in the QoL scores of general cardiac and LQTS pediatric patients may indicate that similar psychosocial treatment plans may be warranted.
- Pediatric LQTS patients may benefit from a multidisciplinary, biopsychosocial treatment team approach, particularly in addressing the impact that LQTS has on a patient's overall QoL.
- Currently, it is not standard practice for all physicians to offer psychosocial services to patients diagnosed with LQTS⁶ who often present to cardiologists as "well" patients in comparison to other "sick" cardiac patients.
- Barriers may include lack of awareness of the need for referrals for psychosocial services, not having psychologists or therapists available on staff, and lack of awareness of appropriate outside referrals or referral lists⁶.
- Interdisciplinary collaboration between physicians and psychologists may provide a useful service to physicians in addressing the needs and concerns of their patients.

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